

Guam Cancer Passport

A Guide to Survivorship & Care

(Revised December 2015)



Remi Pangan

September 1, 1958 - June 21, 2010

This booklet is lovingly dedicated in memory of Remi Pangant, Chairperson of the Guam Comprehensive Cancer Control Coalition (2009-2010) and member of the Cancer Survivorship and Quality of Life Action Team that spearheaded the preparation of this booklet. Without her efforts and driving force, this booklet would not have been possible.

What Cancer Cannot Do

Cancer cannot cripple LOVE
It cannot shatter HOPE
It cannot eat away PEACE
It cannot destroy FRIENDSHIP
It cannot suppress MEMORIES
It cannot silence COURAGE
It cannot invade the SOUL
It cannot steal eternal LIFE
It cannot conquer the SPIRIT

"It gets easier as time goes by. Don't give up."

- Jaimie Quintanilla, youth survivor



Latte Stones - Courtesy of Kavita Hemlani Re'

ACKNOWLEDGEMENTS

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Fax: 735-7500

Website: www.dphss.guam.gov Facebook: www.facebook.com/guamccc

References & Resources:

American Cancer Society website – www.cancer.org National Cancer Institute website – www.cancer.gov

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We would like to respectfully acknowledge the following courageous cancer survivors who contributed their thoughts and messages of hope for this booklet.



Colorectal Cancer survivor since 2005



Testicular Cancer survivor since 1978



Hubert Recheungel Prostate Cancer survivor since 2000



Ocular Cancer survivor since 2012



survivor since 2012



Hodgkins Lymphoma Cancer survivor since 2005





Coconut Tree, Asan - Courtesy of Rayan Bautista

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Resource Guide

Hospitals:

Guam Memorial Hospital – 647-2330 / 2552 / 2939 Guam Regional Medical City – 649-4764 U.S. Naval Hospital Guam – 344-9340 / 9202 / 9586 (for active duty and retired military and dependents only)

Who do I call for insurance questions?

AFLAC - 989-7810

Medicaid Assistance Program, Department of Public Health and Social Services (DPHSS) –

735-7245/7241/7239/7328

Medically Indigent Program (MIP), DHPSS:

Dededo - 635-7466/7485/7487

Inarajan - 828-7524

Mangilao - 735-7245/7241/7239/7328

Medicare Assistance Program, DPHSS – 735-7421

NetCare - 472-3610

SelectCare - 477-9808

StayWell - 477-5091

TakeCare - 647-3526

TRICARE Area Office-Pacific - 1-888-777-8343

Who provides cancer information and resources?

American Cancer Society Guam Field Office – 477-9451 / 1-800-227-2345

Website: www.cancer.org

Edward M. Calvo Cancer Foundation - 472-6854

Website: www.guamisgood.org

Guam Breast and Cervical Cancer Early Detection Program,

DPHSS - 735-0671 / 72

Guam Cancer Care – 969-2223

Website: www.guamcancercare.org

Guam Cancer Research Center, University of Guam – 735-2988/89

Website: www.guamcancerresearch.org Guam Comprehensive Cancer Control Program,

DPHSS - 735-7335 / 0670 / 0673

Website: www.facebook.com/guamccc National Cancer Institute Cancer Information Service

1-800-422-6237

Website: www.cancer.gov

Where can I go for cancer treatment?

Cancer Center of Guam – 647-4656 FHP Cancer Center – 646-5825 ext. 8220 Guam Regional Medical City – 649-4764 Island Cancer Center – 646-3363 Latte Stone Cancer Care Clinic – 777-3305

What government assistance programs are available?

Catastrophic Illness Assistance Program – 735-7293 Department of Integrated Services for Individuals with Disabilities – 475-4624

Department of Public Health and Social Services:

Guam Breast and Cervical Cancer Early Detection Program – 735-0671 / 75

Supplemental Nutrition Assistance Program (SNAP):

Dededo - 635-7466/7485/7487

Inarajan – 828-7524

Mangilao - 735-7245/7241/7239/7328

Medical Social Services – 735-7168 / 7351 / 7356 / 7174

Guam Behavioral Health and Wellness Center (24-Hour Crisis Hotline) – 647-8833

Guam Medical Referral Office:

Guam office – 475-9350 / 53 Hawaii office – 1-808-228-0242 Los Angeles office – 1-323-770-6177 Philippines office – 011-632-579-5002/3

Guam Memorial Hospital (GMH), Medical Social Services – 647-2451

Skilled Nursing Unit, Medical Social Services – 633-1805 Suicide Prevention Lifeline – 1-800-273-8255

Who can help me with In-home services?

Blessed Intermediate Home Care Services – 647-5121/653-1900

Caring Angels - 989-HALO / 4256

Catholic Social Services – 635-1422

Divine Glory Home Care Service – 486-3410 / 488-8108

FHP Home Health (Hospice provider) – 646-5825 ext. 8473

Guahan Caregivers - 788-8825

Guam Nursing Services – 649-2815 or 649-4000

Guam Visiting Nurses – 646-6877

Health Services of the Pacific (Homecare and Hospice provider) – 647-5355

National Family Caregiver Support Program (NFCSP) – 735-3277

Paradise Home Care - 475-4005 or 988-4005

Who provides social services and/or caregiver respite services?

Ayuda Foundation – 473-3003

Catholic Social Service - 635-1422

Guam Behavioral Health and Wellness Center

(24-Hour Crisis Hotline) - 647-8833

Health Services of the Pacific – 647-5355

National Family Caregiver Support Program (NFCSP) – 735-3277

Salvation Army's Family Services Center – 477-3528



Who can provide transportation services?

Division of Senior Citizens, DPHSS – 735-7382/7011 Guam Cancer Care – 969-2223 Guam Regional Transit Authority – 475-4686 / 16 St. Joseph's Medical Transport – 648-7568

Who do I contact for legal assistance?

Fisher and Associates (Legal Aid Services) – 472-1131 Guam Legal Services Corporation - Disability Law Center – 477-9811

Office of the Public Guardian - 475-3173

Cancer Data and Research Partners

Guam Cancer Registry – 735-2988 / 2989 Guam Cancer Research Center – 735-3036 Guam Cancer Trust Fund – 735-2672 Guam Comprehensive Cancer Control Coalition/Program – 735-7335 / 0670 / 0673

Pacific Regional Central Cancer Registry:

Guam Office – 735-2988

Hawaii Office – 1-808-692-0854

Website: www.pacificcancer.org

Online Resources

National Cancer Institute –1-800-4-CANCER (1-800-422-6237)

Website: www.cancer.gov

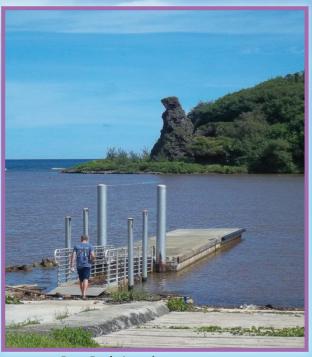
www.medlineplus.gov is a great resource for anything medical. It has a drug dictionary, medical terminology dictionary, and everything about different cancers and their treatments written in understandable language.

My Health Information

Contacts and Phone Numbers My Doctors: _ Clinic: Health Insurance: Secondary Insurance: _____ Policy Number: Pharmacy: _____ Emergency Contact Person: Contact Number: Medical Contact Person: Social Worker: **Medical History** Allergies: Medications: Other Medical Information:

"Get all the help you can, be as educated as you can and stay strong. Pick up positive people in your life."

- Bob Koeppen, survivor



Bear Rock, Inarajan - Courtesy of Kavita Hemlani Re'

Chapter 1

Being Told You Have Cancer

Step 1: Understanding Your Feelings

You have just been told by your doctor that you have cancer. You will have many feelings and your feelings can change from day to day, hour to hour, or even minute to minute. Some of your feelings may include denial, anger, fear, stress, anxiety, depression, sadness, guilt, loneliness and numbness. All these feelings are normal.

Being HOPEFUL is also normal. No one is cheerful all the time, but while you are dealing with cancer, HOPE can be an important part of your life.



You will experience both positive and negative thoughts. Choose to linger on the positive while you work through the negative. Remember that cancer when caught early, and sometimes even in its later stages, can be overcome.

Your journey toward healing may take months or even years, but it is not impossible. It will be a long, and may be for some a short battle, but in the end one wins with strength, will and determination. It is important that you learn and understand your disease well. Know what your options for care are both on-and off-island. Learn all you can.

Learn about the type of cancer, its stage, treatment options and available care on-island and off-island. Ask your doctor the hard questions, read about it and search for people who had it.



2013 Relay For Life Survivor Caregiver Victory Lap
- Courtesy of American Cancer Society

"I was lucky enough to have such great support... people who listened..."

- Tishawnna Smith, survivor

Learn from their experiences and stories. Learning and knowing about your diagnosis will help you make informed decisions about your health care. The road to recovery begins by knowing what your options are at every step of the way.

There are times you may feel alone, but know that you are not. In 2008, there were an estimated 12.7 million people worldwide who were diagnosed with cancer. Every year between 2008 to 2012, an estimated 381 people were told by their doctor that they had cancer.

Knowledge is power. Learning all you can about your cancer will allow you to maintain a sense of control over the diagnosis and help guide your decision making.

Take this booklet with you to your healthcare provider to help you understand your cancer. Let this passport be your guide. Keep it on hand as a ready reference to remind you of questions to ask your doctor.

"I'm supposed to be the strong one, but she's stronger than I am. She went from the negative to the positive and just moved on with life."

- Triny Aguon, mother of youth survivor Jaimie Quintanilla



Rocks and Waves, Asan Beach - Courtesy of Rayan Bautista

Chapter 2

What is Cancer?

Step 2: Learn more about your type of cancer and its treatment.

Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer is not just one disease, but many diseases. There are more than 100 different types of cancer. Most cancers are named for the organ or type of cell in which they start. For example, cancer that begins in the colon is called colon cancer. Cancer that begins in the basal cells of the skin is called basal cell carcinoma.

Cancer in humans has been written about from the dawn of recorded history. Egyptian mummies and fossilized bone tumors from ancient times have been found to have evidence of cancer. The Greek physician Hippocrates (460-370 B.C.), called the "Father of Medicine," is credited with originating the word cancer.

2 What is Cancer

Cancer diagnosis is made by a doctor. A patient's signs and symptoms are not enough to know whether or not cancer is present. If your doctor suspects cancer, you will need to have more tests done, such as x-rays, blood tests, or a biopsy. In most cases, a biopsy is the only way to tell for sure whether or not cancer is present.

To do a biopsy, a piece of the lump or abnormal tissue is removed and sent to the lab for analysis. A pathologist (a doctor who specializes in diagnosing diseases) looks at the tissue under a microscope to see if it contains cancer cells. If there are cancer cells, that doctor tries to figure out exactly what type of cancer it is and whether it is likely to grow slowly or more quickly. Scans can measure the size of the cancer and whether it has spread to nearby tissues. Blood tests can tell doctors about your overall health and can show how well your organs are working.

2 What is Cancer

To help remember what the doctor says, you may take notes or ask whether you may use a tape recorder. You may also want to have a family member or friend with you when you talk to the doctor — to take part in the discussion, to take notes, or just to listen.

Checklist of Things	to	Bring to	Doctor's	: Visit
() Tape Recorder				

- () Notebook
- () Pen
- () Test Results
- () Questions to ask the Doctor

"It's okay to laugh and to laugh as soon as possible."

- Carla Borja, caregiver



Courtesy of Marisha Artero

NOTES PAGE

Ask your health care provider (health care provider includes doctors, nurses, and any others involved in your treatment and healing).

What type of cancer do I have? Notes:	
	112121
	W

NOTES PAGE

Where is my tumor/lump? Please show me where.





2 What is Cancer

What stage and size is my cancer?

Please explain what this means.
STAGE:
SIZE:

Staging is the process of finding out how much cancer there is in the body and where it is located. Staging the cancer is a key step in deciding your best treatment choices. It also gives your health care team an idea of your outlook (prognosis).

Staging can take time and people are usually anxious to begin treatment right away. But do not worry that the staging process is taking up treatment time. In most cases, it is OK because by staging the cancer, you and your health care team will know which treatments are likely to work best.

NOTES PAGE

Has the cancer spread to other parts of my body? If so, what parts of my body? How does this affect my treatment?

Notes:		
V		<u> </u>

Notes:

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What is my prognosis as you see it?

Chapter 3

Understanding Treatments

Step 3: Learn what treatments are being recommended by your doctor and all that is involved.

The three major types of treatment for cancer are surgery, radiation, and chemotherapy. Depending on the type and stage of the cancer, two or more of these types of treatment may be combined at the same time or used one after another.



FHP Cancer Center, Tamuning
- Courtesy of FHP

NOTES PAGE

Treatment Recommendations

What treatments are you recommending? Why? How quickly do I have to make a decision about my treatment?

Notes:	
	1-1-1-1-1
What is the goal of treatment?	
Nata	
Notes:	
	V

Understanding Treatments ———

NOTES PAGE

What are the possible risks or side effects of this treatment? Notes: What are the pros and cons of my treatment? Notes:

Understanding Treatments

NOTES PAGE

Are there other treatments for me to consider?
Notes:
How often will I need to come in for treatment or
tests?
Notes:
Is the treatment available on Guam? If not, where
do you recommend I seek treatment?
Notes:

3

Understanding Treatments -

What are the names of the drugs I will need? What are they for?

Other questions to ask your doctor may also include:

- What if I miss a treatment?
- How will my life change? Will I need to make changes in my work, family life, and leisure time?
- What other drugs or treatments may I have to take?
- How will I know that my treatment is working?
- Why do I need blood tests and how often will I need them?
- If other specialists take part in my care, who will coordinate my entire treatment program?
- What symptoms or problems should I report right away?
- If I don't feel sick, does that mean the treatment is not working?
- Will the medicine/treatment you are recommending be safe to take with the current medication I am taking?

"I was afraid, but I put that on pause... ask the questions so you can move forward."

- Deanna Palmer, survivor



Orchids - Adelup - Courtesy of Diana Santos

3 Understanding Treatments

- What are the chances that my cancer may come back (recur) with the treatment plans we have discussed?
- What can I do to be ready for treatment?
- Will I still be able to have children after treatment?
- Are there any particular foods I should or should not eat?
- Can I drink alcohol beverages?
- Will I need to make changes to physical activity exercises or can I still be physically active/exercise?
- What is the best time to call you if I have a question?

Getting a Second Opinion

Now that you have learned more about your disease, diagnosis, and treatment options, you may now be ready to seek a second opinion. Every patient who is diagnosed with cancer is encouraged to seek a second opinion. A second opinion involves going to a different institution and seeing a

Understanding Treatments

qualified doctor(s) who is/are specialists in treating your type of cancer. It may involve consultation with a medical oncologist, radiation oncologist, and surgeon. It is best if you can meet with them as a team so they can explain your cancer and you can ask questions. It is important to seek their opinions and understand the disease better because:

- Cancer is a very serious disease that can grow rapidly. If it is not diagnosed properly the first time, precious time will be lost that may lessen your chances for recovery and survival.
- The doctor is human and could make a mistake.
- Another doctor could see something that one doctor does not see.
- A specialist could have more experience and know more about your type of cancer.

This is an especially good idea if you feel uncertain about the proposed treatment. For example, if you have prostate cancer and a urologist (a doctor who specializes in diseases of the urinary organs in females and the urinary tract and sex organs in males) has recommended surgery, you may want to see a radiation oncologist to learn about non-surgical treatment.

Consider getting a second opinion when:

- You want to be sure you have explored all options, including clinical trials.
- You think the doctor underestimates the seriousness of your illness.
- The doctor does not know what is wrong with you.
- You have a rare or unusual cancer.
- You think there may be another treatment available.
- Your insurance plan requires it.

Understanding Treatments

Before you begin looking for a second opinion, contact your insurance provider to find out what your policy covers. Many insurance companies will cover a second opinion if your doctor requests it.

Once you have decided who you will see for your second opinion, ask that your medical records, original x-rays, and test results be shared with the referral doctor. You will need to sign a release of information form or you may want to take copies of your medical records to the new doctor yourself. Be sure to take all your medicines (including vitamins and supplements) with you on your first visit. It is advisable to request copies of all your medical tests and diagnosis. Keep them in a safe place so you can refer to them.

The new doctor will review your medical history, prior test results, do a physical exam, and may suggest more tests.

"Hodgkin's is the one that you can cure, right? Yay, cause I wanna be cured!"

- Deanna Palmer, survivor



Two Lover's Point - Courtesy of Rayan Bautista

Chapter 4

Making Decisions

Step 4: Decide on your treatment(s) based on facts.

Now that you know your available treatment options, you must make an informed decision about how to proceed with your treatment and care. Although you may still be emotional at this stage, you must make decisions based on facts, NOT on the emotions of the moment.

Ask as many questions as you need to. Do not hesitate. No question is unimportant. Write down your questions as they come to mind. Bring them with you to the doctor. Some healthcare professionals can focus better on what you are asking when the questions are written. The more questions asked, the more you can clear doubts, and cope with uncertainties.

Chapter 5

Treatment Details

Step 5: Start your treatment with a positive attitude and learn to cope with changes in your body.

Questions to ask your healthcare provider:		
If I choose surgery:		
How much of my will be rem	noved?	
How long will I stay in the hospital?		
Will I need follow-up care?		
When can I get back to my normal activities?		

"You cannot just pretend to be there with your life going on...you have to know what is going to be the outcome."

- Egmidio Babasa, survivor



Hila'an - Courtesy of Marisha Artero

5 Treatment Details ——

If I choose radiation/chemotherapy/hormonal therapy:

When will I start my treatment? When will it

end?		
Start Date:		
End Date:		
How long will each individual treatment last?		
hours minutes		
How often will I need to come in for treatment?		
Can I work during treatment?		
Will I have limitations in my daily living?		

What side effects will I experience? Will you give me something for my side effects?

What physical changes will I experience?

Will there be pain from the treatment and will you give me something for pain?

What emotional changes will I feel? Is there anything you can recommend for my emotional changes?

What else can I do to help my treatment work best?

What are the best foods to eat during my cancer treatment? Is there anything I should refrain from eating?

After being diagnosed with cancer, you or your caregiver might also find it helpful to keep a daily log or journal. Designating a special notebook for this purpose can allow you to capture the everyday details, to include medications taken, side effects you are experiencing, how you are feeling, etc. Your daily entry can be as simple as 1 or 2 sentences a day or as detailed and lengthy as you would like it. Ultimately, taking the time to capture this personal information

will help you be able to accurately report details to your doctor at a later date. Be sure to date your entries for accuracy and to bring the log/journal with you to your appointments and procedures so you'll have the information readily available to share with your physician. Having your log/journal with you at appointments will also allow you to jot down what transpired in your appointment, while the information is still fresh in your memory.

Coping with Physical and Emotional Changes

When you have cancer and when you are having treatment for cancer, you go through changes. Cancer and its treatment can change how you look and feel.

Some of the changes may include:

- Surgery can leave scars or change the way you look.
- Chemotherapy can cause your hair to fall out.
- Radiation can make you feel tired.
- Some drugs may cause you to gain weight or feel bloated.

Treatments can make it hard to eat.
 They may up set your stomach and make you throw up or they can make you feel so sick that you do not want to eat. Some treatments can make it harder to get pregnant or father a child.

Cancer treatment can last for weeks or months. The good news is that most of these side effects go away when the treatment is over. You will want to know as much as you can about side effects, even before treatment begins. This way, you can talk with your doctor about ways to treat them.

Your self-image can change because of the effects of treatment. For example, you may experience the following:

- Your body is not the same as it was.
- If you are single, your dating life may be awkward.
- Your sex life may change.

If cancer surgery changes the way you look, you may want to have reconstructive surgery. If a part of your body needs to be amputated (removed) because of cancer, a prosthetic device (an artificial or man-made body part) can replace what was removed. Cancer treatment may cause you to lose your hair. You may want to cover your head and keep protected from the sun. You may also feel that wearing a wig or scarf improves your appearance and attitude.

Coping with these changes can be hard. But, over time, you learn to accept them. You learn to accept your new self-image by:

- Staying involved in life.
- Getting help when you need it, and talking openly about sex and feelings of closeness with loved ones.

"Now, I am living day by day. I don't think too much about this sickness."

- Hubert Recheungel, survivor



Talofofo Falls - Courtesy of Kavita Hemlani Re'

Chapter 6

After Treatment

Step 6: Be vigilant and follow your doctor's advice to have regular check-ups.

Health care providers cannot tell you if the cancer will come back, but will suggest frequent check-ups. It is natural for anyone who has completed cancer treatment to be concerned about what the future holds.

You may be concerned about the way you look and feel, and about what you can do to keep the cancer from recurring (coming back). You will want to know which doctor will follow you, how often to see the doctor for follow-up appointments, and what test you should have. Understanding what to expect after cancer treatment can help you and your loved ones plan for follow-up care, make life-style changes, and make important health-related decisions.

6 After Treatment ——

You should request a comprehensive care summary and follow-up plan from your doctor once you complete your treatment. You should ask your doctor the following questions once cancer treatment ends. The answer can help inform you about your care and what to expect next.

viriat treatments and drugs have r been given:
How often should I have a routine visit?
What are the chances that my cancer will come back
or that I will get another type of cancer?

6 After Treatment —

What follow-up tests, if any, should I have?
How often will I need these tests?
What symptoms should I watch for?
If I develop any of these symptoms, whom should I call?

6 After Treatment ——

What are the common long-term and late effects of		
the treatment I received?		
What should I do to maintain my health and		
well-being?		
Will I have trouble getting health insurance or		
keeping a job because of my cancer?		

You may find it helpful to write these questions down and take notes or tape record your discussions with the doctor to refer to at a later time.

"Prayers. Prayers really got us through everything."

- Triny Aguon, mother of youth survivor Jaimie Quintanilla



Inarajan Pool - Courtesy of Vivian Pareja

Chapter **7**

Speak Out and Reach Out

Step 7: Talk to someone and seek out your family and friends to support you while you are going through your journey with cancer.

Take time for yourself. Your cancer will not only change your life, but also lives of those around you. Cancer impacts families in many ways. Talking about cancer can be hard for some families. Routines of family life may change. Roles and duties within the family will change. Relationships can be both strained and strengthened. Dealing with money and insurance often becomes hard. You may need to change where you live and with whom, at least for a while.

Once you **accept** that you have cancer, you often feel a sense of **hope**. As acceptance sinks in, you may find it much easier to speak out.

"My dad was my biggest supporter...
he was my everything. Family was
always there. Through every up and
down. A lot of downs."

- Jason Murphy, survivor



Sunset, Tanguisson Beach - Courtesy of Rayan Baustista

7 Speak Out and Reach Out

Cancer is hard to deal with alone. Although talking about your cancer can be hard at first, you may find that sharing your thoughts and feelings helps you deal with your cancer. As you think about how cancer has changed your life and your family's life, consider reaching outside your family to get help.

Talking to someone is a powerful way to conquer all the negative feelings and gives you a positive attitude to move ahead. It frees you and allows you to concentrate on your treatment. It permits you some relief from the worries and fears. It points a guiding light in the midst of the darkness.

Many people also find faith as their source of support. You may find that talking to a leader in your religious or spiritual community can be helpful. Just knowing that you have a circle of people for support can make your journey a lot lighter.

"Don't delay anything...you don't want to do that with cancer. Stay POSITIVE."

- Jason Murphy, survivor



Rainbow, Chalan Pago - Courtesy of Vivian Pareja

7 Speak Out and Reach Out

People you can turn to for help include your family and friends, others who also have cancer, support groups, spiritual help, health care providers, and caregivers. Living with a serious disease such as cancer in not easy. You may worry about caring for your family, keeping your job, or continuing daily activities. Concerns about treatments and managing side effects, hospital stays, and medical bills are also common.

Doctors, nurses, and other members of the health care team can answer questions about treatment, working, or other activities. Often a social worker can suggest resources for financial aid, transportation, home care, or emotional support. Meeting with a social worker, counselor, or member of the clergy can be helpful if you want to talk about your feelings or concerns.

Friends and relatives can be very supportive. Many people also find it helps to talk with others who have cancer. People with cancer often get together in support groups. In support groups, you and your family members meet with other patients and/or their families to share what they have learned about coping with disease and the effects of treatment. It is important to keep in mind, however, that everyone is different. Ways that one person deals with cancer may not be right for another. You may want to ask a member of your health care team about advice from cancer patients.

The important point to remember is that you do not have to be alone in your journey. Widen your circle, seek family assistance, and find the support of other survivors in your community. You will be amazed that there are always people who are compassionate, willing to listen, and helpful in every way.

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2013 Relay For Life Opening Ceremony- Courtesy of American Cancer Society

"How does one survive cancer? Of course

- good doctors, good insurance, good luck.
But the real healing comes from not being
forgotten. From attention, from care, from love,
from being surrounded by a community of those
who demand information on your behalf,
who advocate and stand up for you when you are
in the weakened state, who sleep by your side,
who refuse to let you give up,
who bring you meals, who see you not as a
patient or victim but as a precious human being,
who create metaphors where you can imagine
your survival."





National Family Caregiver Support Program









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